Asian Nursing Research 10 (2016) 201–206

Contents lists available at ScienceDirect

Asian Nursing Research

journal homepage: www.asian-nursingresearch.com

Research Article

Other Side of Breast Cancer: Factors Associated with Caregiver Burden

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ARTICLE INFO

Article history:
Received 19 June 2015
Received in revised form
4 May 2016
Accepted 16 May 2016

Keywords:
breast
burden of illness
carcinoma
caregivers

SUMMARY

Purpose: This study aimed to determine factors associated with caregiver burden among primary caregivers of women with breast cancer in Iran.
Methods: This was a descriptive correlation study conducted in 2012 on 150 main caregivers of patients with breast cancer who came to the oncology clinic of Shahid Ghazi hospital in Tabriz, Iran. A questionnaire which included caregiving-related factors and the Zarit Burden Interview was used for data collection after its validity and reliability were determined. Data was analyzed using SPSS 13.0 software with descriptive and analytic statistics. The association between significant variables and the dependent variable with an observation of the effects of other variables was assessed using the multiple linear regression model.
Results: The mean age of caregivers was 39.60 ± 13.80 years old, and 77 (51.3%) of them were men. The mean score of the Zarit Burden Interview was 30.55 ± 19.18. In the regression model, the mean score of activities of daily living, level of education, gender, and financial status were identified as the determining factors of the burden of caregivers.
Conclusions: Primary caregivers need to be financially supported by the relevant organizations. Care skills training and providing palliative care seem helpful in reducing the pain and the burden of family caregivers for patients with breast cancer.

Introduction

Breast cancer is the most common cancer in women worldwide [1]. Breast cancer in Iran includes 21.4% of all reported cases of cancer. The crude incidence rate of breast cancer in Iran was 4 per 100,000 women. Available data showed that this illness has taken on a raising trend across the country, and from 1999 onwards has recorded the first place among other cancers [2]. Iranian women, compared to other women, are diagnosed with the disease a decade earlier. The highest incidence of this illness in Iran is observed at the ages of 40–49 years [3]. In fact, this disease occurs at the height of the women's family responsibilities and career.

During the disease and treatment, the family is the most involved in caring for the patient; helping them adapt and manage their disease [4]. Today, factors such as decreased family size, reduced presence of family members at home, reduced length of hospitalization of patients at medical centers have increased the length of care at home, and the responsibility of families for taking care of the patient has become more difficult [5]. Therefore, caregivers experience a high burden of care caused by greater responsibilities and changes in their family and social life.

Lu et al [5] quoted that Zarit defined the caregiver burden as a physical, psychological, and social response of the caregiver, which arises from the imbalance between care needs and the several care tasks. This imbalance relates to social roles, personal time, physical

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http://dx.doi.org/10.1016/j.anr.2016.06.002

and emotional state, caregivers' financial resources, and official care resource.

A few frameworks have been presented on caregiver burden. Some have described caregiver burden from both an objective and subjective point of view. Objective caregiver burden is observable and is introduced as a needed effort to provide for the patient's needs. It is identified by the number of hours spent on giving care, types of treatment, service and any imposed financial matters due to giving care. Subjective pressure rises from beliefs, assumptions, and feelings about the role of caregiver [6].

Care, as a source of stress, can severely threaten mental, physical, and social health. Evidence indicates that caregiver burden is a predictor of anxiety, depression, and the low quality of life of caregivers [7]. However, caregiver burden will exist either overtly or covertly, therefore identifying the underlying factors seem to be helpful in modifying it.

Various studies have described diverse factors for caregiver burden including personal and social characteristics of the patient and caregiver [8,9], characteristics of care such as duration of care [8], health status of the caregiver [9] and patient's characteristics [10]. In Eastern cultures, cancer is known as an incurable disease, and in some cases, the concept of death itself. It seems that it can affect the amount of burden on patients and their families; however, very few studies have examined the burden experienced by this group of caregivers in Iran.

Cultural issues seem to also be among modifiers of caregiver burden. The relationship of background factors and caregiver burden has been investigated in western countries, yet the Asian culture is different from the western culture [6]. There is a strong family bond in Iran. Traditional and religious norms enhance the formation of extended family protective networks, and influences the expectations of the amount of caregiver's involvement in giving care. Therefore, effective factors must be identified based on the culture of each society.

This study aimed to determine factors associated with caregiver burden among primary caregivers of women with breast cancer admitted to the oncology clinic of Shahid Ghazi hospital in Tabriz, Iran.

Methods

Study design

The present study was a descriptive correlation study, conducted in 2012 to determine factors associated with caregiver burden among primary caregivers of women with breast cancer in Iran.

Setting and samples

The participants in this study were 150 primary caregivers of patients with breast cancer admitted to the oncology clinic of Shahid Ghazi hospital in Tabriz. The study inclusion criteria for the patients were as follows: (a) being at least 18 years of age, (b) able to identify the primary caregiver and (c) included after at least 8 weeks from her diagnosis. A primary caregiver was defined as a family member, relative, or friend of the patient, who was considered by the patient as the main provider of unpaid care (i.e., spent the most time with the patient, providing the main needed day-today care, assistance, and support) to her. Caregivers fitting the inclusion criteria included those who were 18 years of age or older, not receiving any payment for providing care, participated in the study willingly, and understood the Persian language. Participants were excluded if cancer was diagnosed in caregivers within the prior year or they were receiving cancer treatment, had a known mental disorder or were taking care of more than one patient. The sample size was estimated using G*Power Analysis version 3.1 for a power level of .80, a significance level of .05, and moderate effect size to enable the planned analyses. A sample size of 110 subjects was calculated. Given the probability of a 10% loss of samples and for a higher accuracy, at least 125 participants were being considered. For a higher assurance, 150 caregivers participated in the study. A convenient sampling method was used in the present study.

Ethical considerations

This research was done after acquiring approval from the Research Council (EC130-5/4/11445-11-30) of Tabriz University of Medical Sciences. After coordinating with officials, authors introduced themselves to the participants and explained the purpose of the study. In addition, we assured them confidentiality and the right to withdraw from the study at any time.

Measurements

The data collection tool was a questionnaire consisting of two parts; the first part included demographic characteristics and factors associated with caregiving. Demographic information included age, gender, marital status, educational level, employment status, perceived income adequacy, perceived health status over the past year, hours dedicated to patient's care during the week, coresidency status, treatment method, patient's source of income, and a patient's dependency in performing activities of daily living (ADL).

In this study, dependency in ADL was assessed based on the Katz Index of Independence in Activities of Daily Living and the Lawton Instrumental Activities of Daily Living Scale [11,12]. Both were validated in Iranian culture [13,14]. This scale has 9 items (including dressing, eating, bathing, medication, going outdoors, walking, financial affairs and shopping) based on the 4-point Likert scale (*completely independent* to *completely dependent*). It takes about 2 minutes to complete. A higher score means that the patient is more dependent. The second part included the Zarit Burden Interview (ZBI) which measures the degree to which caregivers perceive care responsibilities as having an adverse effect on their physical health, emotional well-being, social life, financial status, and interpersonal relations. ZBI is a self-report questionnaire including 22 items based on a 5-point Likert scale. Questions from 1 to 21 are answered based on the following levels of frequency: 0 = *never*, 1 = *rarely*, 2 = *sometimes*, 3 = *quite frequently*, and 4 = *nearly always*. Question 22 assesses the overall burden that a caregiver feels; it is scored based on the following possibilities: 0 = *not at all*, 1 = *a little*, 2 = *moderately*, 3 = *quite a bit*, and 4 = *extremely*. The sum of individual item scores ranges from 0 to 88 (total score). Higher scores indicate higher levels of burden or distress felt by a caregiver. Although some authors proposed cutoffs to interpret the results [15,16], we chose to avoid categorizations by cut-offs that were not yet culturally or clinically validated. The time to administer was stated in the main version of the questionnaire, but in our experience it took about 5–15 minutes to complete.

ZBI is widely used in North America and Europe to measure the burden experienced by family caregivers in caring for the elderly with disabilities [5]. However, this tool has also been used for patients with cancer [17]. In Iran, this questionnaire has been validated by Navidian et al [18], and its reliability has been determined at .94. In the present study, the face and content validity of the questionnaire was reassessed, and through Cronbach α, the ZBI and independency in ADL reliability was estimated at .86 and .87, respectively.

Data collection/procedure

Data collection was carried out conveniently in the oncology clinic in 2012 by a trained researcher. Caregivers who fulfilled the including criteria were allowed to participate in the study. Copies of the questionnaires were distributed among participants. Sufficient time was provided to complete the questionnaires. We presented them small gifts after the questionnaires had been filled out.

Data analysis

Data analysis was performed using SPSS (version 13; SPSS Inc., Chicago, IL, USA). First, descriptive statistics were extracted (mean, standard deviation, absolute and relative frequency) and then inferential statistics was examined using the SPSS. The t test and analysis of variance were used in order to compare the difference in the mean of burden according to background characteristics. The Pearson correlation coefficient was used for the study of the correlation of burden with age, length of illness and ADL.

All independent variables with a $p < .20$ [19] from univariate analysis were entered into a multiple linear regression model. In multiple regression analyses, the stepwise method was used in order to arrive at the final model and deduce a multivariate summary model of determinants of the outcome variables. The independent variables in this study were a mixture of continuous and categorical variables. In multiple regression analyses, the categorical variables with more than two groups were coded as "dummy variables" [19]. All assumptions of linear regression analysis (linearity, normality and independence of error terms, as well as multicollinearity of independent variables using the variance inflation factor of tolerance were examined. A p value < .05 (two-sided) was used to denote statistical significance. The Regression Coefficient and 95% confidence intervals were reported to consider the strength of association.

Results

In this study, 150 caregivers of patients with breast cancer who referred to Shahid Ghazi hospital in Tabriz in 2012 were studied. The mean age of the caregivers was 39.60 ± 13.80 years, and 77 of them (51.3%) were male and the rest were female. The mean age of patients was 50.43 ± 10.58 years, and about 40.65 ± 4.91 months had passed since their diagnosis. In addition, 35.7% of the patients had an independent source of income.

In performing daily activities, in 26.7% of the cases, caregivers helped the patients in dressing, 20.0% in eating, 29.4% in bathing, 15.5% in going to the bathroom, 44.6% in taking medication, 14.8% in going outdoors, 28.7% in walking, 36.7% in financial affairs, and 65.3% in shopping. Other background characteristics of the caregivers are summarized in Table 1. The majority of the participants were concerned about the cost of treatment (68.7%) and did not have enough income for living expenses (62.7%). Nearly half of them (49.4%) had abandoned their jobs because of caregiving responsibilities.

Mean caregiver burden was 30.55 ± 19.18. The correlation between caregiver burden with caregiver age ($r = .30$, $p < .001$) and ADL ($r = .51$, $p < .001$) was statistically significant. But the patient's age ($r = .00$, $p < .959$) and length of illness ($r = .02$, $p < .758$) had no significant correlation with the burden. The relation between caregiver burden with the other variables is given in Table 2. Most of the assessed variables were significantly related to burden except insurance, existence of revenue for the patient and acquiring help from others.

In the regression model, an increased mean score of ADL, level of education (illiterate, elementary and middle school education level compared to high school and university education), male gender, abandoning one's career, and perceived income inadequacy were determinants of caregiver burden in caregivers of patients with breast cancer. The coefficients of the variables affecting the caregiver burden in the multiple linear regression analysis are shown in Table 3. It is noteworthy that the recommended model explained 59.8% of the variance of the outcome variable (burden of the caregiver) ($R^2 = .59$).

Table 1 *Sociodemographic Characteristics of Respondents (N = 150).*

Characteristics	Variables	*n*	%
Gender	Male	77	51.3
	Female	72	48.0
Education	No formal education	17	11.3
	Elementary	22	14.7
	Secondary	25	16.7
	High school	47	31.3
	University	38	25.3
	Missing	1	0.7
Relationship to patient	Spouse	52	34.7
	Parents	13	8.7
	Children	47	30.7
	Sibling	21	14.0
	Other	17	11.4
Missing job because of caregiving responsibilities	Yes	20	13.3
	No	129	86.7
Perceived health status in past year	Bad	32	21.3
	Moderate	55	36.7
	Good	63	42.0
Getting help from others	Yes	40	26.7
	No	100	66.7
	Missing	9	6.0
Employment status	Employed	61	40.7
	House wife	43	28.7
	Retired	16	10.7
	Not employed	27	18.0
	Missing	3	2.0
How often do you care for patient?	Weekends	24	16.0
	Daily but during specific hours	27	18.0
	Daily & continuously	91	60.7
	Missing	8	5.3
Residence status	In same house	98	65.3
	In the neighborhood	11	7.3
	Away from patients' home	35	23.4

Discussion

This study aimed at determining the burden of care in caregivers of women with breast cancer admitted to the oncology clinic of Shahid Ghazi hospital in Tabriz, Iran. Modern research trends place an emphasis on the importance of the experiences of the family members of patients with breast cancer and the study of caregivers of different cultural groups [20].

The mean caregiver burden was 30.55 ± 19.18. This mean was higher than that of most other studies that used the same scale to evaluate caregiver burden [17,21,22]. This could be the result of strong family ties in Iran; as a qualitative study in Iran, this study showed that caregivers "bear the entire burden of this responsibility alone and do not leave the patient for even a short time" [20].

However there are some other studies that have reported a mean higher than that of our study [9,23]. These differences may be related to the sampling method, such as sampling based on the stages of the disease. Grunfeld et al [17] in a longitudinal study, selected women with breast cancer who were at the start of palliative care and then in the end stages of the disease. In their study, the difference of caregiver burden between these two periods was statistically significant (Mean = 26.20 vs. 19.40; $p = .02$). Wang et al

Table 2 *Relation between Associated Variables and Caregiver Burden.*

Factors associated with caregiver burden	Variables	Mean (SD)	t/F	p
Gender	Male	35.44 (18.80)	$t = -3.58$	< .001
	Female	25.11 (16.03)		
Marital status	Single	24.51 (17.07)	$t = -2.46$	< .001
	Married	32.68 (18.25)		
Education	No formal education	47.05 (18.00)	$F = 12.00$	< .001
	Elementary & secondary	36.25 (17.37)		
	High school	26.00 (16.97)		
	University	22.28 (13.59)		
Relation to patient	Spouse	39.71 (16.93)	$F = 8.18$	< .001
	Parents	32.22 (21.65)		
	Children	24.88 (17.49)		
	Other	25.23 (15.17)		
Employment status	House wife	26.09 (17.46)	$F = 3.32$	.022
	Employed	35.83 (15.83)		
	Retired	28.93 (15.46)		
	No employed	26.77 (20.87)		
Abandoning job because of caregiving responsibilities	Yes	36.95 (17.08)	$t = 4.46$	< .001
	No	24.39 (17.28)		
Missing job because of caregiving responsibilities	Yes	46.70 (14.65)	$t = 4.50$	< .001
	No	28.14 (17.47)		
Enough income for living expenses	Yes	21.04 (12.71)	$t = -5.52$	< .001
	No	37.45 (17.97)		
Known illness	Yes	35.69 (20.91)	$t = 2.33$	.021
	No	28.12 (16.57)		
Perceived health status in past year	Bad	41.47 (18.84)	$F = 10.26$	< .001
	Moderate	30.45 (16.44)		
	Good	24.58 (16.79)		
Residence status	In the same house	34.64 (18.13)	$F = 6.44$	< .001
	In the neighborhood	23.45 (14.65)		
	Away from patients, home	20.67 (15.43)		
How often do you care for patient?	Weekends	23.12 (16.49)	$F = 3.81$	.024
	Daily but in specific hours	28.70 (16.66)		
	Daily and continuously	33.96 (18.50)		
Concern about cost of treatment	Yes	33.54 (18.03)	$t = 3.09$	.002
	No	23.05 (16.60)		
How many hours a week do you give care to patient?	< 7	25:00 (13.96)	$F = 3.23$	.009
	7–13	18:00 (20.55)		
	14–20	22.90 (17.28)		
	21–26	28.50 (15.63)		
	> 26	35.60 (18.38)		

[24] had pointed out that the burden of caring for critically ill patients who need more care compared to patients who need outpatient care was higher. The organ which is involved with cancer can also be the cause of difference in caregiver burden in different studies [21]. Patients with different types of cancer have different symptoms and treatments. As a result, caregivers experience different care burden. However, some studies have not distinguished the type of cancer [9,23]. Differences in accessing care and support services, social networks, and cultural differences can also cause differences in the reported results. The study by Higginson and Gao [22] in the south of England on patients with advanced cancer, showed lower care burden (18.5 ± 11.0). The researchers interpret these contradictory findings as being due to receiving home-based palliative care services by all participating patients and caregivers; therefore, the care burden of the caregivers was decreased. Nevertheless, in the present study, the participants were deprived of such an opportunity. It is also presumed that the gender of the patients could also be the cause of differences [25]. In this study, all patients were women with breast cancer.

Table 3 *Predictors of Caregiver Burden in Multiple Linear Regression Analysis.*

Variables	*B*	*SE*	β	*t*	*p*
Constant	−4.96	7.82		−0.63	.524
ADL	1.26	0.17	.47	7.14	< .001
Less than high school education	6.74	2.71	.17	2.49	.017
Male gender	6.50	2.53	.17	2.56	.012
Abandoning job	−6.15	2.55	−.16	−2.41	.018
Enough income for living expenses	6.66	2.80	.16	2.37	.019

Note. ADL = activities of daily living; *SE* = standard error.

The regression model test results showed that the mean score of ADL, education level (elementary or middle school education level compared to university education), male gender, abandoning one's career, and inadequacy of income were determinants of care burden. In this study, the male caregivers, who were mostly the husbands, were one of the determining factors of higher care burden. In contrast, in Cumming's study [26], the female gender of the caregiver was introduced as a determinant of the higher burden of care. It should be noted that in the present study most of male caregivers were the spouse of the patients, and it seems that a spouse caregiver had greater physical and emotional closeness to the patient and felt more responsibility towards caring. This could result in a higher burden of care in male caregivers. Cancer is a disease which has a huge impact on the daily role and performance of the family, especially the spouse. In this regard, evidence indicates that the spouses of cancer patients incur the highest burden [27].

In addition, Lopez et al [28], in his qualitative study on male caregivers of women with breast and gynecological cancer, concluded that gender-related attitudes prevent male caregivers from supporting themselves. Male caregivers face their care-related problems in a masculine way, such as minimizing disruptions, focusing on tasks, and keeping their own stress to themselves. They

argue that sufficient research on male caregivers as a distinct group with specific needs has not been undertaken.

In the current study, 60.7% of the caregivers reported that their earnings do not support their living expenses. Regression test results showed that financial problems, in the form of abandoning one's career and inadequacy of income for living expenses, is another factor affecting the burden. This is consistent with other study results [8,9,21]. Due to the economic problems in most developing countries, the above mentioned findings are justifiable. For instance, in a qualitative study [20] in Iran on the caregivers of breast cancer patients, the greatest concerns of the caregivers were insufficient insurance coverage and the high cost of treatment. Despite the mentioned problem, in the Iranian culture, family members and even relatives try to help the patient wholeheartedly because they feel an extreme commitment towards the patient [20]. Therefore, they wish to have much more money to meet all their patient's needs. Nevertheless, some studies claim that caregivers pretend that they receive less support in order to be able to maintain a sense of being independent [29].

In this study, only 35.7% of patients had an independent income source. Furthermore, the majority of the caregivers were the spouses of patients that are the main providers of the family in the Iranian culture. Therefore, when the husbands have to spend the majority of their income on their spouse's treatment, they suffer a great financial burden. On the other hand, in this study, 49.4% of caregivers had to leave their jobs to perform care tasks, such as attending appointments and procedures such as chemotherapy and radiation therapy with patients, and providing medication. In addition, 13.3% reported that they were fired from their jobs while taking care of their patients. These matters have an adverse impact on the economic situation of the family, and thus, burden on the caregivers. This was also shown in the study by Wang et al [24] where, social and financial support, as the most important factors, justified 37.2% of variance of caregiver burden in cancer patients.

Recently in Iran, the health sector evolution program is in implementation. Its first phase began in May 2013 and one of its main objectives is the financial support of refractory patients and patients with special needs. It is hoped that this program can somewhat reduce the pain of cancer patients and their families.

In the present study, an educational level lower than high school was one of the factors affecting care burden; this result confirmed the results of previous studies [9,21]. In the study by Papastrus et al [9], a lower educational level placed more burden on the caregivers ($p < 0.05$). They proposed that perhaps those with higher educational levels use problem-focused coping skills in dealing with difficulties instead of emotional coping skills. However, in a recent study, the relationship between caregiver burden and educational level was not significant [8]. This was probably related to the classification of education; in that study, an educational level below the secondary school was not considered.

In the present study, the caregivers helped patients with daily activities such as dressing (26.7%), eating (20.0%), bathing (29.4%), going to the bathroom (15.5%), and taking medication (44.6%). The study by Biggati et al [27] also showed that a significant proportion of spouses of women with breast cancer reported helping their spouses with daily activities.

In our study, the dependence of daily activities was one of the factors in the caregiving burden which also had parallel findings to previous studies [8,10]. Dependency in daily tasks imposes a physical and mental burden on the caregivers, and causes exhaustion. On the other hand, caregiving limits the caregivers' participation in social activities and entertainment activities, and therefore increases the burden of care. This issue emphasizes the importance of receiving more support and help; nevertheless, supportive care is not available in Iran, even for the cancer patients [20].

The advantage of the present study was the exclusive selection of breast cancer patients, because different cancer types have different symptoms and treatments, and thus, the burden of care in their caregivers is different. Another advantage of the study was that the patients were women, who were mothers and wives, and only the care burden of caregivers of this certain group was measured.

The cross-sectional nature of the data and self-selected subjects were the limitations of this study. Process of care varies with disease progression, and cross-sectional studies do not show the difference in burden and emotional health of caregivers in response to changes in the health of the patient; therefore, longitudinal studies are recommended.

Conclusion

This research provides a better understanding of cancer caregivers' burden and helps identify caregivers who are at higher risk of caregiver burden. Our findings have implications for clinical practice and research.

According to our findings, the primary caregivers who must provide comprehensive care needs support. In this study, the caregiver burden was related to financial issues. It seems that families, especially primary caregivers, need to be supported by relevant organizations, such as government agencies and charities. Given that the financial support of the health sector evolution program is implementing in Iran, we recommend a similar study be conducted after that.

The ADL status is another factor that could impact caregiver burden. As such, dedicating a place for caregivers in the clinic to receive care skills training from expert nurses can be effective. In addition, interventions such as palliative care for patients, could increase patients' ability and therefore calm caregiver burden to some extent.

According to our findings, the level of education could predict the variance of caregiver burden as well. Given that usually a low level of education is associated with lower socioeconomic status and also caregivers with a high level of education are supposed to use better coping strategies, comprehensive support seems vital for caregivers with low level of education. In this regard designing and implementing various supportive interventions seems necessary.

Men, especially husbands, take on additional household chores and take care of patient and family needs that they may not usually be responsible for. As such, they need more attention from researchers as the negative impact of the cancer on their wellbeing is recognized.

Finally, since the nurses are in close contact with caregivers, we recommend that they pay more attention to caregivers' needs in the nursing curriculum.

Conflicts of Interest

No conflict of interest has been declared by the authors.

Acknowledgments

Our appreciation goes to patients, caregivers, physicians, and staff of the oncology treatment center of the hospital who helped in the process of this study. The research project was supported by the Vice chancellor of research of Tabriz university of medical science.

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